Public Health Data Standards Consortium
Privacy Confidentiality and Data Sharing Workgroup
March 5, 2003 12:30 ET

Chair:

Jonathan Lawniczak
Director, Government Relations
AcademyHealth

Members:

Suzie Burke-Bebee, M.S., B.S.N., R.N.
Health Informatics Specialist
Centers for Disease Control and Prevention (CDC)
National Center for Health Statistics (NCHS)

Marjorie Greenberg, M.A.
Chief, Classifications and Public Health Data Standards
CDC/NCHS

Carol Stocks, R.N., M.H.S.A.
Assistant Data Coordinator
Agency for Healthcare Research and Quality (AHRQ)

Jessica Townsend, M.P.H.
Bureau Chief, Health Statistics & Data Management
Health Resources & Services Administration

Michelle Williamson, B.S., B.S.N., R.N.
Health Informatics Specialist
CDC/NCHS

Starla Ledbetter, M.H.S.A., R.H.I.A.
Assistant Manager, Patient Discharge Data
California Office of Statewide Health Planning and Development oshpd

Questions for Kathleen Fyffe at Steering Committee meeting (slides attached)

The workgroup would like to ask Kathleen Fyffe the following questions:

- Covered entity providers are not releasing information due to liability concerns. If they have one million records with five separate fields they might be liable for five million releases. How will OCR communicate to these providers that it is OK to release the data?
- If a researcher violates a data use agreement, will it fall back on the provider?

- What will OCR develop to counter these concerns?
- Workgroup would like OCR to explain to people about the implications for research and public health.
- How will OCR outreach to public health departments?
- Local health departments are really concerned about how to think about being a hybrid entity, how to erect firewalls, how to conduct training, and how to detail the healthcare functions.
- This workgroup would like to partner with OCR and would like to ask her if she has an idea of what type of project that might be. Suggestions included a checklist, guide, or algorithm to serve as an adjunct to data release guidelines.
- Where is the product of the work done by NIH as information for research? Seven fact sheets and a booklet were sent before Thanksgiving, but all but the booklet have been held up due to clearances.
- OCR has been focused on covered entities, but where is the information for public health?
- What plans are there to evaluate the impact of HIPAA, not just covered entity compliance, but the actual impacts on data releases—not just anecdotally?
- Will OCR be documenting the various excuses for not releasing data, so that materials can be developed to counter these arguments?
- Can she provide information about the new departmental approval process?

John will gather any other questions from the workgroup and submit them to OCR prior to the Steering Committee meeting if possible.
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II. Modifications to Charter Document

This was discussed on the last call. No modifications have been sent, so the document must be acceptable. The revised charter has not been sent out after first comments, so John will send it out. When the revised charter is released, it will be posted on the listserve.

III. Comments on Data Release Guidelines Working Group on CDC-ATSDR-CSTE
 The Data Release Guidelines for Re-release of State Data (attached) has been sent to the workgroup for comment. The workgroup discussed whether comments should be from this group or from individuals. Workgroup members are to look at the document and submit changes to John by March 24 to coordinated the responses. Marjorie will send this forward once it has been compiled by March 31.   Carol expressed concern that the document is troubling because is explicitly says safe harbor method is inadequate for health departments because public health collects more demographics than covered entities.   Since public health has higher standards for privacy than HIPAA, covered entities might think it is necessary to raise the bar for all privacy and that would put up more barriers. If de-identified information is not good enough, that might backfire on public health. There is also interesting language that you need to follow up on how data is being used. If public health is required to do that, the covered

entities might think they need to do that and will refuse to conduct that much work. These comments will be included in our comments when we send them. .

IV. Review of NCVHS letter to Secretary Thompson for potential functions of committee (attached)

The letter from NCVHS to Secretary Thompson is a place where this workgroup might get ideas for functions for this committee. These questions arose from discussion of the letter:

- What mechanisms will be set up for public health to get questions answered? While OCR answers questions from covered entities, there is not a current mechanism to answer public health and research.
- Will there be targeted guidance for specific groups?
- How will commercial research get files from CMS as they have stated that CMS files are available only for pure research? Who can answer these questions?
- Has anyone pulled together a document to discuss the pros and cons of becoming a hybrid entity and how or whether to do that?

V. Partnership ideas

The workgroup discussed the fact that it is hard to reach out because the workgroup has not yet determined its own focus. The annual meeting will probably spark a lot of ideas from Steering Committee members. The Consortium may play a role in bringing together the crosscutting issues and may need to develop a new set of FAQs or a new document to raise these issues. The Steering Committee will be asked for questions after John's presentation. Also the round table discussions held on the first day may also bring out some privacy related issues. The workgroup is always open to new membership.

Action Items:

- Additional questions for Kathleen Fyffe to be sent to John
- John to send the revised charter document out to all members of the workgroup
- Comments on the Data Release Guidelines to be sent to John for compilation by March 24
- Marjorie to send the compiled responses forward by March 31